Nutritional Management of Children with Medical Complexity

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September 7, 2023

SickKids®

I (we) would like to begin by acknowledging the land on which SickKids operates. For thousands of years it has been the traditional land of the Huron-Wendat and Petun First Nations, the Seneca, and most recently, the Mississaugas of the Credit River. Today, Toronto is home to Indigenous Peoples from across Turtle Island. SickKids is committed to working toward new relationships that include First Nations, Inuit, and Métis peoples, and is grateful for the opportunity to share this land in caring for children and their families.

Art by Emily Kewageshig

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Presenter Disclosure

- Relationships with commercial interests:
  - None

Learning Objectives

- Describe Children with Medical Complexity (CMC)
- Briefly review nutritional assessment of CMC
- Discuss common interventions for the nutritional management of CMC
  - Growth and Anthropometrics
  - Gastrointestinal Issues
  - Enteral feeding
  - Blenderized Tube Feeding (BTF)
  - Micronutrient deficiencies
- Review guidelines for monitoring and follow up

Children with Medical Complexity (CMC)

Individuals with:

- Presence of ≥1 complex chronic conditions; often multisystem & severe
- Significant functional limitation requiring technology (e.g. feeding tube)
- High health care utilization from different providers
- Caregiver identified high health care service needs

Account for <1% of all children but significant health-spending

Dewan & Cohen, 2013

Nutritional Assessment of CMC

- Anthropometrics
  - Head circumference
  - Weight
  - Length (<2 years) & height (>2 years if ambulatory)
  - Segmental length
  - Body Mass Index (BMI)
  - Mid-arm circumference, triceps skinfold, mid-arm muscle mass

- ESPGHAN recommends using WHO growth curves
- Disease-specific curves are growth *references* with limitations
  - Small sample size
  - May be based on children already suffering from malnutrition

Nutritional Requirements of CMC

Estimating Energy Needs

- Recommended use of WHO equation and an activity factor of 1.1 x Resting Energy Expenditure (REE)
- Use the following equations to determine REE*

Age Range (years)	Males (kcal/d)	Females (kcal/d)
0 – 3	60.9W – 54	61.0W - 51
3 – 10	22.7W + 495	22.5W + 499
10 – 18	17.5W + 651	12.2W + 746

*Use as a starting point and titrate feeds based on weight response

World Health Organization, 1985; Marchand, 2009

Adjusting Energy

- Most children with NI have **decreased energy needs** compared to healthy children, even with spasticity
- Guide recommendations based on response from therapy
  - Excessive weight gain ⇒ decrease calories by ~10%
  - Suboptimal weight gain ⇒ increase calories by ~10%
- No standardized recommendations for frequency of follow-up
  - More frequently for infants or unstable children (e.g. 1-3 months)
  - Less frequently for older, nutritionally stable children

Adjusting Protein

Protein

- No guidelines have been developed for protein requirements in children with disabilities
- Patients are at risk for protein insufficiency
  - Are often already protein-wasted, due to inactivity and poor dietary intake
  - Low energy requirements/intake = low protein intake
  - Are at high risk for pressure ulcers, already have them

- Start with an estimation using the RDA/DRI
  - US National Pressure Ulcer Advisory Panel recommends **(adults):**

    1.25 – 1.5 g/kg

- Consider using high-protein formula for children with ulcers or low caloric requirement
  - Higher-protein and adult formulas
  - Combination of adult & pediatric formulas
  - Addition of protein modules ($)

Adjusting Fluid

Fluids

- Usual maintenance requirements may not be appropriate
- ↑ requirements due to excessive losses
  - Drooling
  - ++ Sweating
- ↓ requirements for patients with inactivity and muscle wasting
- Typically, 75-100% of maintenance may be adequate and can be adjusted based on clinical status

Children with Medical Complexity: GI/Nutrition Sequale

Chronic problems in 80-90% of children with CP or other NI include:

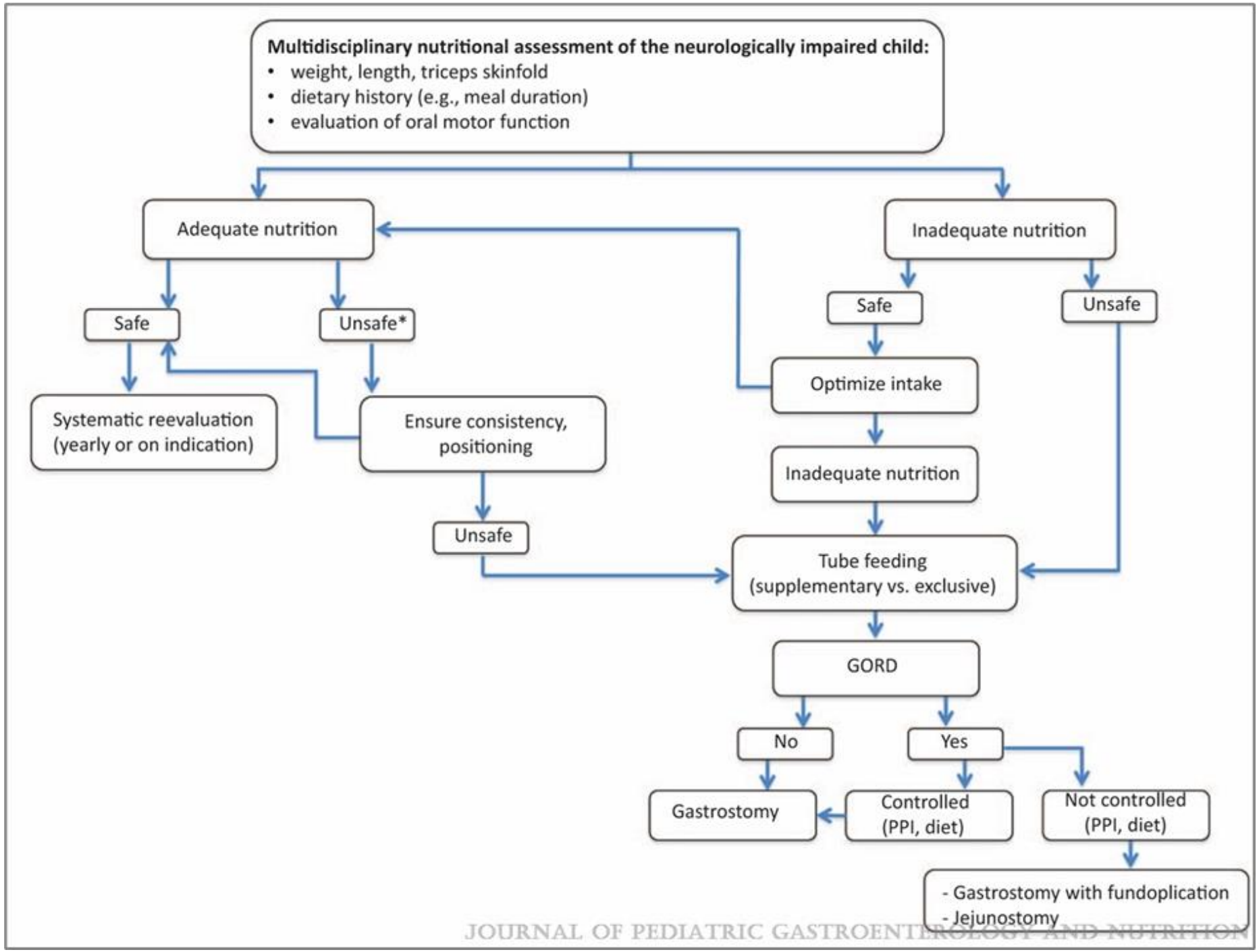
- Malnutrition
- Feeding disorders
- Gastroesophageal Reflux Disease (GORD/GERD)
- Constipation
- Delayed gastric emptying
- Diarrhea

Chong, 2001; Marchand et al., 2006; Sullivan, 2008; Penagini et al., 2015

Oral-Motor Issues

- Poor oral motor control
  - ⬇ intake
  - ⬆ aspiration risk
- Liquids are difficult to manage
  - Loss of liquid from front of mouth
  - Premature escape of bolus into oro-pharynx > aspiration risk
  - Often better with bottle feeding
- Purees easier to manage
- Immature chewing skills
  - Oral motor skills correlate with developmental level & not chronological age

Marcus & Breton , 2013



ESPGHAN, 2017

Clinical Signs of Swallowing Issues

- Coughing/choking with oral feeds
- Change in voice quality during oral feeds
- Poor secretion management
- Sudden, significant drop in oxygen saturation with oral feeds
- Sudden, significant drop in heart rate with oral feeds
- Resistance to oral feeding
- Recurrent chest infections
- Recurrent unexplained fevers

Is aspiration from above or below?

Marcus & Breton, 2013; Miller, 2011; Tutor & Gosa, 2012

Feeding & Swallowing Interventions

Thickening Liquids:

- Thickened liquids improve swallow function when:
  - Oral motor control is decreased
  - Pharygeal response is slow or delayed
  - Airway protection is compromised during swallowing
  - Reduced sensory or cognitive awareness

Thickening purees:

- If pharyngeal clearance is an issue thicker purees may be worse

Khooshoo et al., 2001; Kuhlemeier et al., 2001; Logemann, 1998; Marcus & Breton, 2013

Feeding & Swallowing Interventions

- Positioning:
  - To maximize oral motor function, air way protection
  - To improve suck, swallow, breathe coordination
- Bolus size/Method of presentation:
  - Slow flow versus fast flow nipple
  - Spoon versus cup
  - Open cup versus spout or straw
- Speed of presentation of bolus:
  - Sequential swallows versus single swallows with cup
  - Pacing sucking bursts & pauses with bottle
- Increase sensory input:
  - Modify temperature, taste, bolus size, texture

Marcus & Breton, 2013

Gastrointestinal Issues: Symptoms

GI Issue	Symptoms affecting oral feeding
GERD	Pain or discomfort part way through feeds Feeds well at beginning of feed but limits intake Vomiting may or may not be seen
Delayed Gastric Emptying	Decreased hunger Nausea, Gagging Vomiting- sometimes hours after a feed
Constipation	Decreased hunger Nausea, Gagging Vomiting Abdominal pain
Diarrhea	Malabsorption Dehydration

Marcus & Breton, 2013

Gastrointestinal Issues: Interventions

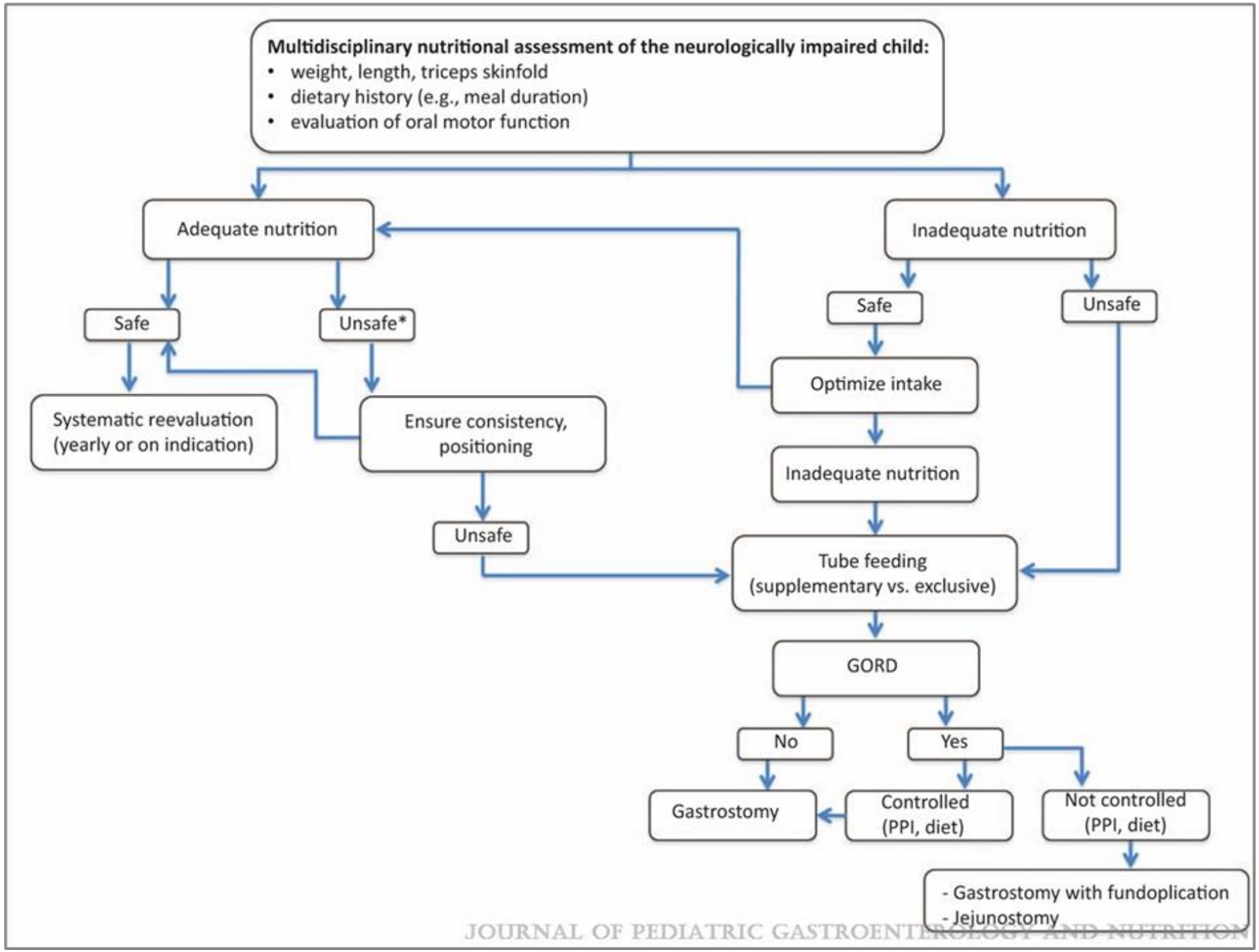
GI Issue	Symptoms affecting oral feeding
GERD	Medication- Acid blocker, prokinetics Extensively hydrolyzed or amino acid-based formula Positioning Blenderized tube feeds Continuous feeds, Consider post-pyloric feeds
Delayed Gastric Emptying	Prokinetics Extensively hydrolyzed or amino acid-based formula Blenderized tube feeds
Constipation	Ensure adequate hydration PEG 3350 2-3 oz prune juice Increase fibre
Diarrhea	Use of probiotics W/U for bacterial overgrowth Extensively hydrolyzed or amino acid-based formula Blenderized tube feeds

Arvedson, 2008; Chong, 2001; Marchand, 2006; Penagini et. al., 2015; Sullivan, 2008 ; Vandenplas et al., 2009

Oral Feeding in Context

- Consider the overall goals of feeding:
  - Optimize nutrition & growth
  - Quality of life (child & family)
  - Improve safety of oral feeding
  - Increase oral motor skills +/- wean enteral nutrition

- Oral feeding goals may change over time



ESPGHAN, 2017

To Tube Feed or Not to Tube Feed

- Energy boost
- Adjust feeding schedule to stimulate hunger & thirst
  - Set time limits; structure feeding times
- Trial different formula (change taste; improve tolerance)
- Guide appropriate food/fluid choices > work with feeding therapist/parent
- Ensure adequate fluid volume (maintenance fluid) & nutrient distribution

To Tube Feed or Not to Tube Feed

- Decision to initiate is multi-faceted:
  - Medical
  - Financial
  - Cultural
  - Emotional

- Interdisciplinary team required

- Supplemental vs total enteral nutrition (EN)

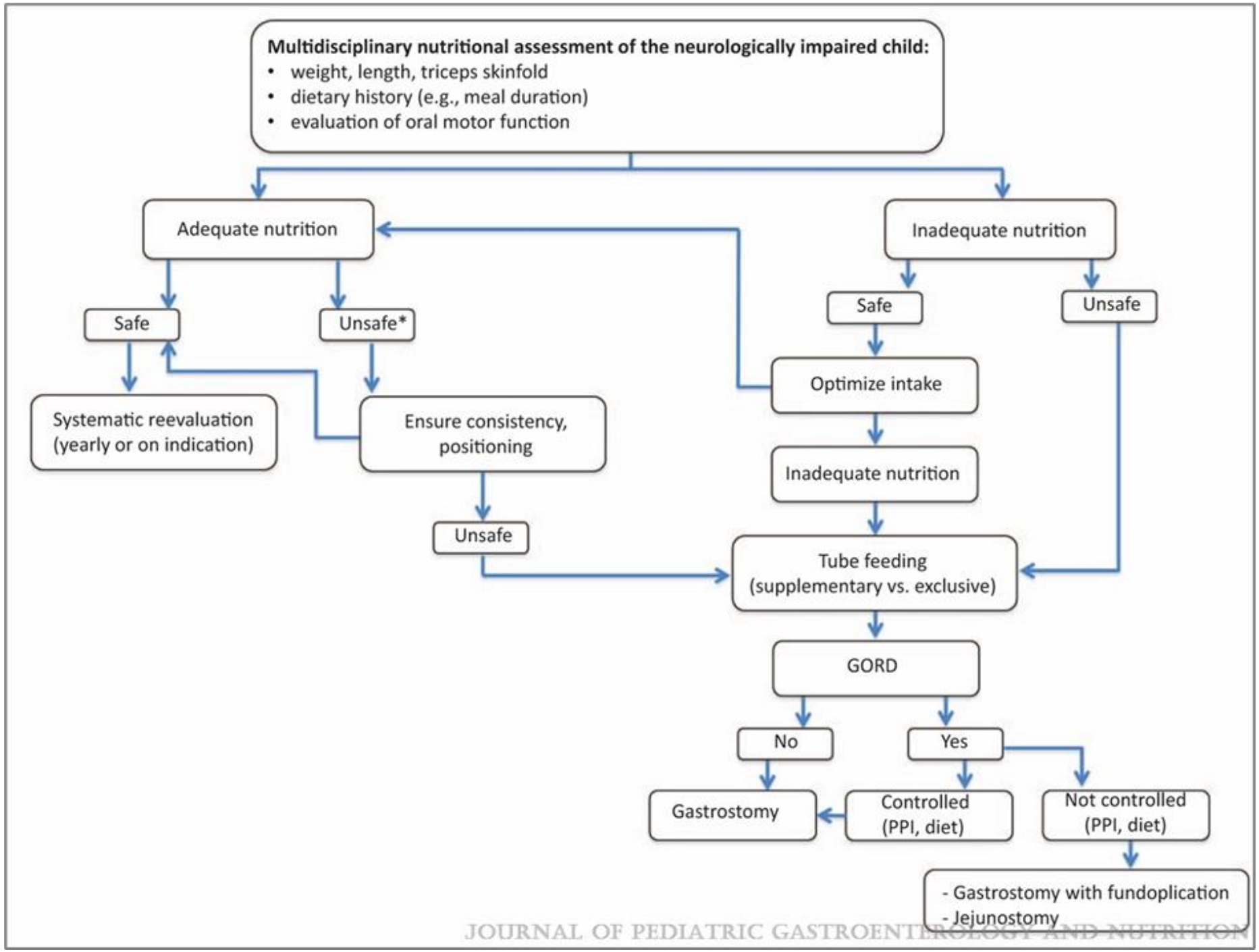
Adams et al., 2014

Family Experiences With Feeding Tubes (Nelson et al., 2015)		
Variable	Benefit	Challenge
Physical Outcomes	Weight gain Improved respiratory status Assured route for provision of fluids & meds	Excessive weight gain GI complications Respiratory complications Difficulties with the tube
Quality of Life	Ability to focus on other activities than feeding	Discontinuation of PO feeding
Socialization	Improved alertness, more interaction	Loss of PO feeding as source of interaction Feeding equipment - mobility
Caregiving & stress	Ease caregiver burden	Intensity of care needs Parental sleep
Parent-Child Relationship	Reduced frustration with PO feeding Improve relationship	Loss of emotional component to PO feeding Loss of normality of feeding
Parent-Medical System	Support of health care professionals	Systems utilization Difficulties with respite care
Other	Potential for family cohesion & sibling involvement	Inadequate access to services & support

Formula Selection

- Infants should receive expressed breast milk or infant formula
- Older children may use standard (1.0 kcal/ml) polymeric feeds
- Blenderized feeds/real-food containing formulas

ESPGHAN, 2017; Johnson et al, 2015; Soscia, 2021; Gallagher et al, 2018



ESPGHAN, 2017

Treatment Options - GERD

- Change in formula e.g., casein -> whey based
- Consider use of hydrolyzed or amino-acid based feed for improved tolerance
- Change in kcal/rate/volume
- PPI – often higher doses are needed (gastric pH)
- Prokinetics
- Post pyloric feeds

TABLE 4. Infusion rates based on Pedrón Giner et al (102) and NASPGHAN (106)

Age	Initial phase rate	Advance rate	Suggested tolerated rate
Preterm	0.5–2 mL · kg^{-1} · h^{-1}	0.2–1 mL/kg every 8 h	4–8 mL · kg^{-1} · h^{-1}
Infant	1–2 mL · kg^{-1} · h^{-1}	1–2 mL/kg every 2–8 h	5–6 mL · kg^{-1} · h^{-1}
1–6 y	1 mL · kg^{-1} · h^{-1}	1 mL/kg every 2–8 h	1–5 mL · kg^{-1} · h^{-1}
≥7 y	25 mL/h	25 mL every 2–8 h	100–150 mL/h

Pedron Giner C, et al. Nutr Hosp 2011;26:1–15.
NASPGHAN. Pediatric Enteral Nutrition: A Comprehensive Review.
Fried et al. J Pediatr 1992; Khoshoo et al. J Pediatr Gastroenterol Nutr 1996;
NASPGHAN. Pediatric gastroesophageal reflux clinical practice guidelines. 2018

Treatment Options – GERD + Blenderized Tube Feeds

What are Blenderized Tube Feeds (BTF)?

- Pureed whole food and liquids administered directly into the gastrostomy tube (G-tube)
- Can be sole source of nutrition, supplemental nutrition, or as a combination of BTFs & formula feeds
- Blenderized feeds have been shown to have benefits (social and physiological), but food safety must be considered, as well as additional cost

Treatment Options – GERD + Blenderized Tube Feeds

Inclusion	Exclusion
Patient Profile	
Medically Stable • ≥1 year of age • Uncontrolled reflux	Medically unstable or acutely ill x ≤85% IBW x ≥5% weight loss in last month
Feed Type	
• Gastrostomy tube ≥ 12 French • Continuous OR bolus feeds • Polymeric, semi-elemental, elemental	x Nasogastric tube (NGT) x Naso-jejunal tube (NJT) x Gastro-jejunal tube (GJ tube)

Implementing Blenderized Tube Feeds

Planning the Schedule:

- Current G-tube feeds may be:
  - Bolus
  - Continuous
  - Combination
- Options for incorporating BTFs:
  - BTFs as 1 meal/day
  - 50:50 (BTF:Commercial Formula)
  - 100% BTFs
- BTFs:
  - Must be given as bolus feeds
  - May be given in conjunction with continuous formula feeds
  - Some equipment is required

Implementing Blenderized Tube Feeds

Some Considerations:

- Ensure variety of foods to meet micronutrient needs
- Salt should usually be added (~1/4 teaspoon/day)
- Introduce whole grains gradually to avoid constipation
- Ensure adequate hydration
- Avoid seedy fruits and vegetables such as berries
- Thoroughly cook/store all foods appropriately

Monitoring Blenderized Tube Feeds

- Routine anthropometrics while establishing blend
  - Every 2-4 weeks while establishing feeds
  - Monthly-annually once established
- Bloodwork
  - Generally not routinely required if diet is diverse
  - Standard suggested bloodwork for clinical presentations (e.g. bone health labs in children with medical complexity)

Treatment Options – Delayed Gastric Emptying/Abdominal Distention

- Using G-tube to vent/decompress (syringe vs Farrell bag)
- Slowed feeds
  - Boluses <15ml/kg
  - Continuous <8ml/kg
- Extensively hydrolyzed/amino acid based formula
- Blenderized tube feeds
- Management of constipation
- Use of prokinetics

Mazzeo & Mascarenhas Curr Probl Ped Adol Health Care 2021;
Phippen et al. BMJ Support Palliative Care 2017

Treatment Options - Constipation

- Formula/diet changes – blenderized tube feeds
- Addition of fluid if safe
- Initial clean out > maintenance treatment (PEG3350, lactulose)
- Additional fibre (can also cause intolerance, distention, flatulence)
- 2-3oz prune juice
- Medications
  - Used for slow transit constipation
  - Can also help improve feeding intolerance/nausea

Monitoring Micronutrients

- Prevalence of micronutrient deficiencies between 10-55% in CMC
- High risk for deficiencies of:
  - Iron
  - Zinc
  - Calcium
  - Vitamin D
  - Vitamin C
  - Vitamin E
  - Selenium
  - Vitamin B12
  - Folic Acid
- Recommendation to provide DRI for micronutrients – monitor yearly unless change in clinical status, growth
- *C-Reactive Protein

Monitoring Micronutrients – Bone Health

- Decreased bone mineral density noted in ~60% of children with NI
- Fragility fracture prevalence: 20% in non-ambulatory children with CP
- Dietary Ca, PO4, Vitamin D are below DRI in 50-80% of children with NI

- Yearly labs
  - Ionized Ca, PO4, 25-OHD, PTH, ALP, urinary calcium/creatinine ratio

- Supplement Ca intake to DRI
  - Monitor for complications (nephrocalcinosis/stones)

- Supplement 800-1000 IU of Vitamin D per day

Coppoloa et al., 2009; Fehlings et al., 2011; Marchand et al., 2009

Monitoring Micronutrients – Jejunal feeds

Children on long-term jejunal feeds:

- Asses 1-2 times/year:
  - Serum Cu + ceruloplasmin
  - Selenium
  - CBC+MCV/ferritin/STR/iron
  - Zinc
  - Albumin
  - CRP
- Supplement via G-tube or orally if possible
- Recheck levels after supplementation in 1-3 month intervals

Broekaert et al., 2019

Monitoring Micronutrients - Recommendations

- No evidence-based guidelines for nutrient allowances specific for CMC
- Standard recommendations of vitamins, minerals and trace elements can be followed with exception of vitamin D, given the increased risk of deficiency
- Other considerations:
    - If there are multiple micronutrient deficiencies, are you able to use a multivitamin vs individual supplements
    - When recommending a supplement, suggest checking what types/formulations are available online (amazon, well.ca) or at your local pharmacy to help guide families
    - Route of administration
    - Cost

Recommended Reading:

SOCIETY PAPER

European Society for Paediatric Gastroenterology, Hepatology and Nutrition Guidelines for the Evaluation and Treatment of Gastrointestinal and Nutritional Complications in Children With Neurological Impairment

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THANK YOU!!

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